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QUALITY OF LIFE IN LONG-TERM CARE INSTITUTIONS:

A CONCERTED APPROACH

Papers by:

Mary Hill and Madeleine Honeyman
Gloria Parker and Pierre Soucie
Paul Pallan and Tim Young
Dorothy Pringle

with the collaboration of

Louise Plouffe

April 1992
National Advisory Council on Aging

Information on this report may be obtained from:

National Advisory Council on Aging
Ottawa, Ontario
K1A OK9
Tel: (613) 957-1968
Fax: (613) 957-9938

Blossom T. Wigdor, CM, PhD
Chairperson

Susan Fletcher
Executive Director

Également disponible en français sous le titre:
Qualité de vie et soins de longue durée en institution: Une approche concertée

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The *Writings in Gerontology* present in-depth examinations of topical issues in the field of aging. The opinions expressed are those of the authors and do not necessarily imply endorsement by NACA.

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WHAT IS THE NATIONAL ADVISORY COUNCIL ON AGING?

The National Advisory Council on Aging (NACA) was created by Order-in-Council on May 1, 1980 to assist and advise the Minister of National Health and Welfare on issues related to the aging of the Canadian population and the quality of life of seniors. NACA reviews the needs and problems of seniors and recommends remedial action, liaises with other groups interested in aging, encourages public discussion and publishes and disseminates information on aging. In carrying out its responsibilities, NACA works closely with the Minister of State for Seniors.

The Council has a maximum of 18 members from all parts of Canada. Members are appointed by Order-in-Council for two- or three-year terms and are selected for their expertise and interest in aging. They bring to Council a variety of experiences, concerns and aptitudes.

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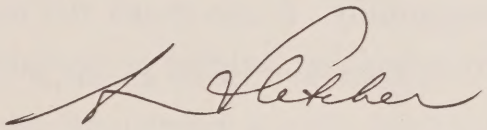
FOREWORD

The *Writings in Gerontology* Series is intended as a vehicle for sharing ideas on topical issues related to the quality of life of seniors and the implications of an aging population. It is produced as part of the National Advisory Council on Aging's mandate to publish and disseminate information and to stimulate public discussion about aging.

The Council endeavours to ensure that the articles in the series provide useful and reliable information. Most of the texts are original manuscripts. Some are written by Council staff, others by experts in their fields.

This series is addressed to seniors and the people who care about their well-being. It is hoped that readers will find the *Writings* useful.

The Council welcomes comments on the topics selected, as well as on the content of the articles.



Susan Fletcher
Executive Director
National Advisory Council
on Aging

PREFACE

The articles collected in this document were initially presented in a panel discussion at the 19th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology held in Victoria, B.C., in October 1990. The panel was organized by the Long-term Care Network. It brought together families of seniors living in long-term care facilities, service-providers and government officials to discuss, from their perspective as consumers, providers or policy-makers, the attitudes, activities, procedures and policies that have a crucial impact on the quality of life of residents in long-term care facilities. From the discussion emerged ways of developing a collaborative approach to fostering autonomy and health and new directions in policy that can ensure that quality of life becomes a central concern in the development of long-term care services.

I thank the members of the panel for allowing the National Advisory Council on Aging (NACA) to publish the articles adapted from their presentations. I acknowledge as well the collaboration of Louise Plouffe, Policy Analyst at NACA, who wrote the articles based on the presenters' notes, and Francine Beauregard and Renée Blanchet, whose fine editing ensured readability. I also thank the members of the Council for their support ensuring that helpful presentations are given wider distribution.

Blossom T. Wigdor

Blossom T. Wigdor, CM, PhD
Chairperson

ABOUT THE AUTHORS

The National Advisory Council on Aging is grateful to the various authors of this publication. They are:

- Mary Hill has been a member of the National Advisory Council on Aging since 1988. She has lectured on the topics of aging, social policy and family needs and published a number of academic papers in the field of social work. Mary Hill, M.S.W., is currently a member of the City of Vancouver Special Council Committee on Seniors and a member of the Board of the Seniors' Resources and Research Society of British Columbia. She is a past president of the B.C. Association of Social Workers.

- Madeleine Honeyman is a well-known educator in the field of pychogeriatrics and mental health. She was the founder and first President of the Alzheimer Society of Ottawa-Carleton (1980-1988). She initiated two special programs, the 'Day Away' and 'Home Assistance Program' to assist those with Alzheimer's disease and their families.

- Gloria Parker is the Director of Care at Tillicum Lodge in Victoria, B.C. She is Past President of the Registered Nurses Association of British Columbia and she has served on the Executive of the Canadian Nurses Association. Gloria Parker was a member of the Canadian Medical Association Steering Committee on Health Care for the Elderly in Canada.

- Pierre Soucie is the Medical Director of the Elisabeth Bruyère Health Centre in Ottawa, Ontario. He is also responsible for the geriatric training program in care of the elderly as Assistant Professor, Department of Family Medicine, University of Ottawa. Dr. Soucie is presently a member of the Ottawa-Carleton District Health Council,

the Board of Placement Co-ordination Service of Ottawa-Carleton and the Steering Committee Role Study of Chronic Care, Province of Ontario Community Health and Support Services Division.

- Paul Pallan is the Executive Director of the Continuing Care Division of the Ministry of Health in British Columbia, as well as Executive Co-ordinator of the Office for Seniors. He is a graduate of the University of Toronto's program in health administration.

- Tim Young is the Director of In-home Services Branch, Community Health and Support Services Division of the Ontario Ministry of Community and Social Services and Ministry of Health. Prior to this, he was both Acting Director and Manager of the Community Programs Unit of the former Elderly Services Branch. He was involved in the planning for Ontario's long-term care reform. He joined the Ontario Public Service in 1975 in research administration.

- Dorothy Pringle has been Dean of the Faculty of Nursing at the University of Toronto since 1988. Previously, she was Research Director for VON Canada. She received her B.Sc.N. from McMaster University, her M.S. degree in psychiatric/mental health nursing from the University of Colorado and her Ph.D. in nursing focusing on care of the elderly in the community from the University of Illinois.

1. THE QUALITY OF LIFE IN LONG-TERM CARE INSTITUTIONS: INTRODUCTION

The quality of life of people receiving long-term care depends on a successful partnership among the recipients, their families, formal service providers and policy-makers. This document identifies concerns involved in making long-term care a resource for living, not just surviving. The authors show how the meaning of quality of life varies, depending on one's perspective. They highlight the policies, procedures, attitudes and activities that have a crucial impact on the quality of life of clients and discuss existing and emerging program elements. The authors stress a collaborative approach to fostering autonomy and health, and the development of policies to ensure that quality of life is a central concern in long-term care services.

THE CONSUMER'S PERSPECTIVE

by

Mary Hill and Madeleine Honeyman

April 1992
National Advisory Council on Aging

2. THE CONSUMER'S PERSPECTIVE

It is impossible to speak about the quality of life in long-term care from the consumer's perspective without referring to the personal experience of caring for a family member or friend or of knowing someone who has heavy caregiving responsibilities for an elderly person. We all have our own stories, our own experiences of being treated well or poorly by the long-term care 'system' either as a wife, a daughter, a daughter-in-law or a friend of a senior in a long-term care facility.

Also, we feel more than empathy for our family members and friends in long-term care. The possibility exists that one, or all of us will end our lives in an institution. Our concern is deeply felt. What we ask is that our relatives or friends residing in long-term care facilities live as normal and as satisfying a life as possible and that we, as families, be able to contribute to their care in a meaningful way.

2.1 Institutional Care: The Ideal and the Reality

The ideal of institutional long-term care is to allow the resident to continue living as normally as possible and to provide environmental support that allows the person to use his or her remaining capacities to the fullest.[1] The ideal implies a resident-centred philosophy, shown in the institutional policies and in the way staff treat residents. A three-way partnership of care involving the resident, the institutional staff and the family is hoped for. In addition, the ideal long-term care establishment provides 'holistic care'--it recognizes the emotional, social and spiritual needs of residents, as well as the needs for nursing and personal assistance. Care plans should be adapted to each resident, to enable individuals to make the most of their abilities and to restore function as much as possible. These plans should be flexible enough to respond to the changing needs of the residents. For example, Mrs. P. can and usually does wheel herself to the dining room without help, but the staff need to respond appropriately

when an acute attack of arthritis in her wrists makes moving about unassisted too painful.

Long-term care institutions vary widely with respect to how well they conform to the model of ideal care. Some facilities do provide a wonderful service; in these places, there seems to be a humane, warm and sensitive feeling toward the residents and the families. However, too many institutions still fall short of ensuring quality of life for long-term care residents and families. The differences between the 'good' facilities and those that are not so good are not necessarily based on budgets or architecture and decor; in our experience, the quality of care has a lot more to do with the philosophy of the board of directors and the administration, as well as with the attitudes and knowledge of the staff.

Why do so many of the institutions where our relatives reside fall so far short of the ideal? Why do they appear so custodial and so unindividualized? Where is the restoration of function, the accent on personal growth and the holistic perspective? So many barriers seem to prevent the realization of the ideal care we want for the persons we love.

2.2 Who is in Charge?

Until serious, disabling illness occurs requiring formal long-term care, the senior and his or her family feel they are in charge; that is, they can make and act upon their own decisions. When the senior is placed in an institution, both the senior and the family feel or often are made to feel incompetent and helpless. Despite the assurances that long-term care is a three-way partnership among the care recipient, the family and the formal caregivers, there is the distinct feeling that a new management has taken over and that none of the former owners or managers are included on the executive team.

Dependency on others for personal care can lead to a parent-child relationship between staff and residents. In the minds of some staff, residents become like children who must have everything done for them and who should be co-operative and well-behaved. This is especially true when the facility is short-staffed and the personnel find it more efficient to do everything for the residents than allow them to perform the basic tasks of daily living at their own pace. For the residents, on the other hand, staff are seen as benevolent authority figures who should be obeyed. Because all the power is in the hands of the institutional 'parent', residents may be afraid to assert themselves for fear of reprisal or withdrawal of whatever attention or affection they get, and even the threat of eviction. Families also may be afraid of the consequences of 'rocking the boat' on their elderly relative.

2.3 Easing the Adjustment

New residents and families need more help than they may get to adjust to institutional placement. For the new resident, there are seldom welcoming gestures, such as a 'newcomer's dinner', nor the assignment of someone in the facility to orient the newcomer for the first few weeks, to introduce him or her to staff and other residents and to serve as the first friend. Residents and families are not often given sufficient and appropriate information about the institution's policies, the roles of staff, nor about the way decisions are made. For example, families may be told to mark the senior's name on every item of clothing, but may not be informed that bedtime is at 8:00 p.m. The move to an institution may provoke feelings of loss and grieving in some seniors and their families. Staff should be especially attentive to new residents to help them accept their loss and make the most of opportunities in the facility.

We are not surprised to discover that new residents may experience depression and that their intellectual functioning suffers upon placement in a long-term care facility. Changing one's lifestyle to conform to the institutional routine can be difficult. Sometimes, counselling is needed in addition to a site visit. A paraplegic resident was devastated to find out that he could not take his electric wheelchair with him to the nursing home; it was bad enough to have to leave his home and wife, he also was losing the basic mobility that was so vital to his autonomy! People also want to feel welcomed in the place that will be their permanent residence. Management might be surprised by the willingness of families and the capacity of residents to assist in newcomer orientation.[2]

The transition is easier when the facility is in a neighbourhood familiar to the resident and when some of the residents are already acquaintances or friends. When the surrounding community is the same, moving to an institution may feel less like being exiled from the wider world.

2.4 Communication and Partnership: Cornerstones of Caring

If a three-way partnership is to mean something, there must be communication among the partners. The administration and staff of the facility must listen to the resident and the family. The small girl who takes her father's face in her hands and says: "Daddy, you have to listen with your eyes" knows that listening involves more than token attention.

If listening and partnership were taken seriously by long-term care institutions, there might be fewer comments like the following:

- "Your mother can't bring her comforter to the lodge; it doesn't match the decor."

- "Go home, Mrs. H., and get on with your life; your husband is now our responsibility."

- "How do you feel about going to a nursing home?" (said to a person in an advanced state of dementia).

In our experience, opportunities for families to talk to other families are not promoted. Worse, residents may not be helped in communicating with other residents. Those who are severely handicapped physically or who are confused may be even more isolated because other residents are afraid to approach them. We worry, too, about residents from other cultures who speak little English or French; how estranged they must feel in a place where nothing is familiar and where they have no one to talk to except the occasional visitor.

2.5 Inadequate Care and Abuse

There are two forms of institutional care: one involves consultation, the other, colonization. In the former, families are consulted by the facility as often as they--and the resident--wish and their advice is taken seriously. In the latter, families and residents are asked about their wishes as a formality, but the caregivers do what they believe is 'best for Joe' and routinely disregard the expressed wishes.

The resident may be neglected. It may not be gross neglect (although gross neglect does occur in a few places, despite provincial 'inspections'); it may simply be less constant care than what the senior received at home, because staff have no time. There can be abuse, although often unintentional. Restraints will be used as a means of controlling a restless resident without consulting the family for alternatives; staff may insist on using tranquillizers or other medication, even if they are contra-indicated for the resident's condition. A bathroom door may be left wide open while a

resident is being toiletted. Staff may scold the resident like a child--for instance, for letting muffins go stale in a drawer! Is it any wonder that seniors dread 'being placed' and that family caregivers will care for seniors at home with insufficient support often longer than their own capacities allow?

2.6 Families: Why Don't They Visit More Often?

As families, we have experienced the feeling of being unwelcome, despite the words in the brochures and the little plaques on the walls of the waiting room. On a family visit to an institutionalized relative, there was no room anywhere for the grandchildren to play and the adults had trouble conversing because the echo off the walls made it hard to hear. We are told that families do not visit their relatives in institutions often enough, despite the institution's encouragement. How is it possible for a working daughter to visit her mother during the week, however, when bedtime is in the early evening? Perhaps families would visit more often, stay longer and become more involved if they could do more than sit in a chair for a 'visit' or if the facilities on the whole were more inviting places--more alive, more open to spontaneity and play and less 'institutional'. The facilities should be a home, not a hospital.

2.7 Difficult Families and Unco-operative Residents

Family members can make it uncomfortable for institutional staff to provide care, although they realize that the nurses and aides are caring and committed human beings trying to do a difficult job. Families know how difficult caregiving can be because they could no longer do it themselves. Most families want to contribute, not to make trouble or discredit the staff.

Drawing the line between legitimate and unreasonable complaints can be difficult. What may seem to be a minor detail or an annoying idiosyncrasy for the institution can be an important symbol of individuality and autonomy for the resident and for the family who tries to intercede on his or her behalf. Institutional regimentation goes against the grain of human nature; when the most important freedoms are lost, people will cling, seemingly beyond reason, to what little control they have.

In preparing this presentation, one of the authors asked a resident of a long-term care facility what she would want to say. She said: "Tell them to remember that I'm human." Residents and families feel that the institution is run for the convenience of the staff rather than for the sake of their well-being. Running an institution for the convenience of the residents might be inefficient, slightly chaotic and possibly risky. Such is human life everywhere else. Protests from families and 'difficult' behaviour on the part of residents are understandable ways of resisting unnatural incarceration and of saying: "I'm human."

Guilt and discomfort may colour the reactions of family members towards institutional staff--guilt that they cannot meet the daily responsibilities of caregiving although they remain committed to caring. Part of the difficulty that institutional staff face in dealing with residents' families may stem from this guilt, in the sense that families are saying to the staff: "To make up for my inability to give care, you must be perfect."

Families want to continue participating in caregiving because they can show their relative, in a normal way, that they care--especially when visits and words become meaningless to a confused resident. Families need to become aware of their feelings about institutionalizing someone they love. Opportunities to talk with other families of residents also help. As well, they want to be informed on how they can share in making the facility a real home, rather than feel guilty, frustrated and intrusive.

2.8 Suggestions

As family members of seniors whose needs we can no longer meet at home, we accept the necessity of long-term care facilities. We recognize the humanity and commitment of many individual staff members. The long-term care facility has the potential and, indeed, the mission to maintain or improve the health and well-being of the residents. We want to work with the staff and administrators to bring them closer to the goal. We offer the following suggestions to the personnel in long-term care facilities, based on our experiences.

- Expect more than passive co-operation from residents and their families; they can and want to be informed, to take initiatives and to be involved in the life in their home.

- Facilitate communication among families, especially regarding institutional policies; create resident and family committees with effective input into institutional decisions.

- Promote communication among residents; give guidance to residents in approaching those with particular difficulties.

- Always respect residents' dignity, privacy and freedom of choice; listen with your eyes.

- Assist new residents and families in adjusting to the facility in ways that are meaningful to them.

CONCLUSION

Seniors in long-term care have suffered losses in their physical or mental abilities to the point that they have become dependent; their sense of personal control is tenuous, at best. Families of these vulnerable seniors try to be their advocates. Their efforts and the capacities of the residents to regain personal control depend upon the long-term care environment. Institutions should play a key role in enabling the seniors in their care to live life to the fullest.

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THE SERVICE-PROVIDER'S PERSPECTIVE

by

Gloria Parker and Pierre Soucie

April 1992
National Advisory Council on Aging

3. THE SERVICE-PROVIDER'S PERSPECTIVE

Services in long-term care facilities are provided by persons in many occupations, including administrators, nurses, doctors, dieticians, rehabilitation therapists, health care aides, maintenance staff, activity workers and social workers. In principle, all share the goal of assuring that residents enjoy an adequate quality of life and that the residents' families remain meaningfully involved in care and support. Because the long-term care facility is the workplace of the service-providers, they too need a working environment which gives them a sense of fulfilment as helping professionals. Indeed, a long-term care facility where residents enjoy an optimum quality of life is the most satisfying workplace for service-providers.

Nevertheless, staff face a number of obstacles which may hinder their capacity to provide the quality of life desired by themselves as well as by residents and their families. The nature and extent of these barriers vary from one facility to the next. Our purpose here is to describe the constraints faced by service-providers in long-term care and to suggest how these can be overcome.

3.1 Developing Shared Values

Families, staff and the residents, all want quality of life in the facility, but each has a somewhat different understanding of what contributes to it; these views may be at cross purposes at times.

Residents value having control over the care decisions affecting them and having privacy and security of their possessions as highly as having their health needs attended to. Service-providers may emphasize caregiving more than resident autonomy and privacy; for example, in one study[1] professionals rated medical care and social activities as being key factors, whereas aides judged the quality of life for residents more in terms of having proper meals, baths and organized activities.

Unless residents, families and the various staff members discuss their respective definitions of quality of life to understand each other's values and priorities and try to reconcile differences, each group may be dissatisfied. Although democratic partnership in a setting that has a clear structure and established lines of authority is difficult to practice, it is essential if quality of life is to be achieved. Quality of life issues in the long-term care setting revolve around:

- a co-ordinated system of care delivery
- a shared value system that allows residents choices and control over their lives
- adequately trained personnel
- care-providers who work together to achieve mutual goals
- adequate funding to support a system that delivers services of quality.

3.2 A Hospital or a Residence?

People move to a long-term care facility because their physical or mental health problems no longer permit them to remain at home with support from the family or the community. Ideally, the long-term care facility is intended to provide the medical and personal care required, while allowing the resident to live as normal a life as possible and to use his or her abilities to the fullest extent possible.

Too often, however, the hospital aspect of the residence environment is more evident than the home aspect. Maintaining uniform standards of nursing care, cleanliness and safety may take priority over the particular psychological and social needs of each resident. Administrators and nursing

supervisors are answerable to hospital or provincial authorities for ensuring that these standards are met. They also feel responsible to families who expect that their relative will be nursed, fed and properly washed. The main duties of the aides are to toilet, bathe, dress and give meals to as many residents as they are assigned. There is much to do; uniformity and efficiency are important and staffing is usually inadequate. Insufficient funding and consequent understaffing lead to strict protocols, routines and dehumanized delivery of care.

Ensuring safety and standard conditions are facility imperatives. Residents who are agitated or noisy may be routinely sedated to minimize disturbance to other residents. For example, a resident may love to sing all the time, as she/he always did at home, but the singing is offensive to co-residents and may lead to resident aggression. Sedation may be given inappropriately simply because there are fewer staff on the night-shift. Electric wheelchairs may be forbidden because hallways are too narrow. Doors may be locked to prevent wandering. Keeping food in rooms may be prohibited in case of insect infestation and bacteria. The fact that these measures are coercive and minimize the opportunity of residents to exercise their remaining capacities have to be balanced with the uniform assurance of safety and hygiene. When individual freedom seems to conflict with the comfort and security of the whole group, the decision is made in favour of the group. Making these decisions can be painful for staff.

Other aspects of long-term care settings, such as having to share a room with one or many residents one does not choose, having little privacy or space for personal possessions and perhaps being obliged to leave (sometimes permanently) when there is a health problem that requires special attention that cannot be given on the premises, create a hospital atmosphere.

The organizational structure may contribute to an impersonal environment for the residents. Union/management contracts and downward lines of authority which often have many levels, leave staff feeling powerless and unable to influence the way care is provided.

3.3 Individualized Care Plans

Providing care in a long-term facility that meets the physical, psychological and social needs of the residents in a home-like environment means tailoring care on an individual basis. Despite the best intentions and efforts of the staff, this may be difficult for several reasons.

One resident may wish to stay awake until midnight, while another is ready for bed right after supper. Some residents prefer to snack rather than comply to a formal meal time. Many cognitively impaired residents become resistant when they are being undressed and bathed; to avoid reactions of fear and indignation, each resident requires a special approach. The best care involves knowing the person's needs, documenting them so that all service-providers are informed and responding to them in a consistent, personalized way.

Despite the sincere efforts of nurses and health care aides, individualized care is difficult to provide. A single nurse or aide may discover what works best with a particular resident, but this information may not be communicated to the staff working other shifts or to other levels of personnel. At times, staff may feel frustrated in their efforts to give care and be reluctant to share the problem with other staff--and even more to share their feelings of frustration for fear of appearing incompetent before supervisors.

Care tends to be task-oriented rather than person-oriented. So many baths to give on Floor 1 and meals to serve in Wing A may be the fashion in which duties are assigned to aides. All baths must be given before visiting hours and the time for each resident is limited. This organization of duties makes it hard for staff to spend the extra 'quality' time with each resident to respond to the whole person, although they would gain a much greater sense of personal gratification from their helping role if they could.

3.4 Autonomy for Residents

Autonomy, like quality of life, is a concept that may mean different things to different people. Freedom to choose in one aspect of living may be more important for one resident, but less so for the next. For some residents, freedom of choice may be as simple as choosing which clothes to wear or selecting meals from varied menus; for others, it may mean having the possibility to take an unsupervised trip actively facilitated by staff. Of course, knowing which choices are meaningful expressions of autonomy for each resident requires a philosophy of individualized care, as well as the staff complement and expertise to follow them through.

Owing to their extensive physical or mental disabilities, residents may appear to be able to do very little for themselves. It may be difficult and time consuming to find out what they actually can and want to do. Care-providers in long-term care facilities can easily have very low expectations of the residents. In planning activities, staff will usually consult residents and take their wishes into account, but will take charge of planning and directing the activity. Residents' councils, where they exist, may have little real input into the institutional decisions because the residents are not thought to be competent enough, or because the membership is unstable owing to illness and death of members, or yet because the residents lack confidence in their ability to make an impact. Most activities are intended for diversion or recreation, rather than to permit residents to learn new and useful skills. In

an environment where there are no expectations of the residents other than to be co-operative, the residents may have few expectations of themselves and may become more dependent than they need be.

An important element of the resident's autonomy is the option to participate in medical and treatment decisions in the event of a sudden collapse and/or in the event of terminal illness or the onset of dementia. When these issues are not thought out in advance, they pose a dilemma for service-providers. Should a resident be put on advanced cardiac life support? Is it possible to provide palliative care to the dying resident who wants to be cared for in the facility until he or she dies? Facility staff are faced with the problem of finding out and documenting the wishes of each resident, as well as trying to comply with these wishes.

A system must be established that provides for an 'advance directive' to be placed on each resident's chart. This directive would help staff comply with the resident's wishes in the event of an emergency. It also identifies a person chosen by the resident to act as a 'health proxy' when he or she is no longer capable of making decisions.

3.5 Making Family and Friends Part of the Team

Families may be regarded with mixed feelings by the institutional staff. On one hand, their presence and support of the resident is known to be vital in maintaining the quality of the resident's life. Family members provide information that is useful in understanding a resident's behaviour or in observing changes that signal problems. Also families often take charge of outings and appointments outside the care facility.

On the other hand, families often have high expectations of care delivery; some may experience a sense of failure and guilt that may make their expectations almost unrealistic. This causes them to be seen as an

interference or a threat by the staff when they seem critical of the staff's efforts or when they do not seem to appreciate the pressures on the staff. The family's insistence on a consistent standard of physical care also may make it harder for the staff to give individualized care to the resident or to allow a certain degree of risk that the resident wants. If a resident is to be given maximum freedom, even if risk is involved, the family must be included in the decision. Their decision to share the risk with the facility should be documented.

3.6 Resident-centred Care: From Theory to Practice

For resident-centred care that meets the needs of the whole person in a setting as close to home as possible, there must be radical changes in the organization of care in many long-term care facilities. The basic problems stem largely from the organization of the facilities, not the lack of motivation or professionalism or good will of individual staff members working in the facility. Fundamental organizational changes require consistent direction and support from the top levels of administration downward. Effective and lasting changes also require the willing participation of the direct-care staff. A few of the possible improvements are described below.

3.6.1 Implementing resident-centred care

Caring for each resident in a way that meets established standards--yet respects the abilities and personality of the resident--requires a concerted effort on the part of all staff involved to get to know the resident and to communicate with one another regarding the preferred way of providing care. The preparatory work of the resident's physician, the facility social worker and the head nursing staff in learning as much as possible about the incoming resident is critical. Time must be spent with the senior and the family prior to and upon admission to determine what quality of life means

to him/her and what kind of choices are important to that individual. These initial in-depth consultations will guide the staff in helping the new resident to compensate for the losses experienced in moving to the facility. In addition to laying the foundation for an individualized care plan, these preparatory efforts will help bolster the morale of the new resident. The resident's acceptance of placement in a long-term care facility is a key element in his or her quality of life.

Staff duties should be reconsidered to give more opportunity for fewer care-providers to attend to one resident for any rotational period. This reorganization would allow staff to know the resident better and find effective ways of individualizing care routines which can be communicated to other staff. Encouraging staff to take initiative in caregiving decisions allows them to develop greater competence and derive more satisfaction from the caregiving relationship. Residents, on the other hand, would have the opportunity to develop more trust in the staff and feel that they are truly cared for as persons.

3.6.2 Establishing real partnerships with residents and families

Allowing families and residents to provide input into caregiving decisions from the time of admission in long-term care and to have recognized collective ways of influencing institutional policies can have significant effects on the quality of life of residents and staff. From the staff's perspective, a collaborative effort can ease the pressures that are regularly felt in trying to meet the conflicting demands of the province and the desires of the residents and their families.

With appropriate encouragement and direction from staff, family members are ready to take on a larger share of responsibility in personal care and in organizing activities for residents. Families and staff also can consult each other when a resident needs more than one or the other can

provide. By reaching out to families and by helping them to understand what the staff are doing, the long-term care facility can enlist the ongoing contribution of families to the quality of life of the residents.

Allowing the resident to direct the care decisions that affect him or her and enabling individuals to make effective use of their abilities show respect for autonomy and minimize the dangers of overdependence. Furthermore, because the staff will be more likely to regard the residents as autonomous adults and be able to identify with them, condescension and violations of personal privacy will be less likely to occur.

3.6.3 Professional education and in-service training

Very little education is provided to professionals for work in long-term care facilities; indeed, there is yet minimal education about aging and the elderly in the health and social service professions. Moreover, many health professionals do not consider long-term care to be interesting and rewarding work. Nevertheless, the professionals on the staff of a long-term care facility are responsible for giving leadership and direction to the non-professional staff in making vital decisions regarding the life and care of residents and in interacting with residents and families. The professional staff must be able to recognize and stimulate the abilities of each resident and to develop individualized care plans. In sum, nursing, social work, occupational therapy and other professional roles in long-term care require extensive knowledge, a high level of skill, creativity and empathy. Improvement in the quality of life in long-term care facilities depends to a large extent on the education of the professionals who assume positions of leadership in the facilities.

The entire staff complement, from senior administration downwards, should receive adequate training regarding aging and the needs of long-term care residents. The nursing aides and orderlies who provide direct care also require training to work effectively with residents who may have multiple disabilities. Much of the training for direct-care staff can be provided on the job by professional staff, as well as through opportunities to share caregiving successes and problems with one another. The administration and the professional staff have a responsibility to the residents and to other staff members to promote constructive exchange and learning among caregivers.

CONCLUSION

Promoting quality of life in long-term care facilities is as important to the service-providers as it is to residents and families. However, staff members can find themselves caught in a system that makes it difficult for them to reach the goal, or even to identify clearly the obstacles to quality of life. Long-term care facilities can simultaneously improve the quality of life of residents and the quality of their working environment by becoming committed to resident-centred care, by forging partnerships with residents and families and by providing the necessary training for all staff.

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THE POLICY-MAKER'S PERSPECTIVE

by

Paul Pallan and Tim Young

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4. THE POLICY-MAKER'S PERSPECTIVE

Before embarking on the priorities, goals and dilemmas of governments in delivering long-term care services, we would like to make the distinction between the government staff who develop policy proposals and administer official policy (that is, legislation) from the political leaders who are more accurately the policy 'makers'. The reason for this distinction is to make the point that the direction of public policy is ultimately decided by elected officials, in a context which includes many factors other than the expertise and recommendations of policy developers within government departments. Among these 'other' factors are political philosophy, public opinion and the state of the economy.

The evolution of public policy is often a slow and cumulative process. Many individuals and interest groups become aware of problems in the system and make representations to government and the media. Policy staff within government also conduct analyses, monitor and evaluate programs and tune into the concerns expressed by individuals and lobby groups. Eventually, the inadequacies of the system become common currency and politicians respond to the popular will by passing new legislation. Of course, the introduction of legislative change can be delayed even further when there do not seem to be viable solutions to the problems everyone recognizes. For the prophets who first identify the problems in government policy, change is never fast enough.

4.1 A Historical Glimpse at Long-term Care: Inherited Attitudes and Structures

Institutional long-term care has undergone radical transformations since the early part of the century,[1] although some of the attitudes that were current at each stage of its evolution still haunt us.

Initially, institutions for the sick, the destitute and the elderly were known as houses of refuge and operated by charitable or religious organizations or by local governments. Residents were called inmates; by virtue of having to depend 'on charity', they gave up personal freedom for total and unquestioned institutional control.

From the middle of the century until the 1970s, institutional care of the elderly came to be viewed essentially as a form of prolonged hospitalization, with facilities classified according to the amount of nursing care required. Facilities were either wings of hospitals converted to chronic care units or they were built using a hospital model: large, functional, impersonal and focused on physical care. Provinces established standards for the buildings and for the quality of nursing and personal care.

The funding arrangements for institutional care and the variations among provinces in the types of service available and their modes of access to long-term care also are legacies of this period.

Costs for medical treatment, nursing and other therapeutic services are shared by the federal government and the provinces. These are universal benefits, although the provinces are free to deliver health care services in the way they deem appropriate.

Personal care, meals and lodging in institutions are another matter. Public funding may be available in some facilities to cover part of these costs, but residents are charged for the remainder. In general, provinces provide coverage for higher levels of care (extended care) with the client contributing a small *per diem*. Until very recently, provincial monies were allocated on the basis of a fixed amount per bed rather than on the basis of the care actually required by each resident. In lower levels of care, depending on the province and the type of environment, the individual may be required to pay as little as the *per diem* fee for extended care all the way up to the full cost of care.

Finally, provinces differ in the extent to which home support and institutional services are co-ordinated and the degree of commercial involvement. Currently, British Columbia and Manitoba have the most co-ordinated systems of care delivery. Long-term care facilities in Quebec, Saskatchewan and Alberta have a high proportion of publicly-owned facilities, while British Columbia, Ontario, Prince Edward Island and Nova Scotia have many privately-owned establishments.

Rising costs of health care and the gradual decrease in the relative contribution of the federal government to the provinces for health care have led to cost-constraint measures. Limits have been placed on the number of long-term care beds and efforts are being made to enhance home support to prevent or delay institutional placement.

Ideas concerning the goals of long-term care have changed in recent years. Broader concepts of health and well-being have led to the understanding that meeting psychological, social and spiritual needs are as important as providing physical care. Expanding knowledge about aging and an awareness of the potential for restoration of function in seniors is gradually leading to a concern for rehabilitation and for maintaining remaining capacities. Increased attention to individual rights and freedoms is reflected in the values of autonomy and empowerment and in client-centred care philosophies.

A number of provinces have proposed major changes in the organization of health care generally, including long-term care. The trend everywhere is to enhance home-based long-term care, on the assumptions that an individual's quality of life is usually better at home than in an institution and that up to a point, home care is more cost-effective than institutional care. Success in implementing these changes at the provincial level will depend on the policies regarding the funding of health care and the reallocation of resources from the institutional sector to the home support sector.

4.2 The Goal of Government in Long-term Care

Basically, governments must try to satisfy the demands of all the players in the system--those of the providers, as well as those of the consumers. Programs must be designed and delivered so that all players emerge as winners. Moreover, the system must operate within the constraints of available resources (physical structures and personnel) and of public finances.

The system should promote the best possible use of available funds. Where the provision of long-term care is in the hands of commercial interests, government considers it more advantageous to gain the co-operation of the industry in adhering to the norms for the well-being of residents than to play an adversarial role.

4.3 The Dilemma Faced by Governments

In light of the expectation that the State has a role in promoting and facilitating the quality of life of all citizens, governments are faced with difficult issues, particularly in health care and social services. Essentially, the government is a partner with the family, the community and the individual in supporting individual quality of life. Society as a whole must decide which needs or demands can and should be met in light of public revenues.

4.4 Specific Roles and Challenges of Government in Long-Term Care

4.4.1 Access to long-term care and continuum of service

Ease of access for seniors who may require institutional placement to the appropriate level of long-term care is uneven among the provinces. Some seniors are placed in facilities that do not provide a sufficient level of care, while others live in places that give more care than is required.[2]

Placement decisions are sometimes made on the basis of the availability of an affordable bed (for the senior), usually in a time of crisis. A co-ordinated system of long-term care with individual case management, as in British Columbia, effectively minimizes inappropriate placement. Other areas of the country are moving in that direction. Within the next few years, it is anticipated that there will be both more extensive home-care services to prevent or delay institutional placement as well as a mechanism to gain timely and appropriate access to institutional care.

We can already foresee that it will be difficult to determine how many institutional beds will be required in the future. Another difficulty is how to base decisions for admission to institutional care, so that all those who need it have access to the most appropriate facility.

4.4.2 Standards of care

One of the major roles of government has been to establish standards of care in long-term care facilities. Standards have evolved over the years in response to public pressure to include services to meet needs for socialization, privacy and resident choice, as well as to improve the physical facilities and ensure high-quality personal care. Facilities are now more accountable to government for the quality of care. Government monitors institutions by means of regular inspection, consultation and a measure of financial support to correct deficiencies or enhance the quality of care. In extreme cases, government can appoint a public administrator or revoke operating licences and close delinquent facilities; these options are used when all other measures have been exhausted.

Problems remain. Facilities that provide strictly residential care, such as retirement homes, are not regulated; some are wonderful even without established standards; others are a disgrace. Inspection procedures in regulated facilities have been criticized because they are not frequent enough and because facilities know ahead of time when they will be

inspected. Moreover, the inspection reports may not be made public, thus preventing the possible benefits of publicity to encourage adherence to standards. Consumer advocacy groups, such as the Concerned Friends of Ontario Citizens in Care Facilities, are playing an important role in spurring public opinion and eventually, government action in this regard.[3]

The standards themselves may set incompatible goals. For example, institutions are required to maintain high standards of hygiene and nursing care; at the same time, they have to respect the individual lifestyles, privacy and personal choices of residents.

Yet another concern relates to the kind and extent of rehabilitative services that should be available in a standard way in long-term care facilities. The Ontario government has been challenged by The Senior Citizens' Consumer Alliance for Long-Term Care Reform to outline current and projected expenditures and distribution of services for physiotherapy, chiropractice, audiology, speech-language pathology, occupational therapy, social work, nutritional counselling, psychology and psychiatry in the proposed reform of long-term care.[4] All these services certainly can contribute to ameliorating the quality of life in institutions. But is government wholly responsible for providing them?

4.4.3 Facility size and design

It is known that smaller facilities provide more staff-resident contact, less institutional rigidity and more personal freedom for residents than do larger institutions. Nevertheless, there are a number of fairly large institutions in many areas; often, the larger chain-operated facilities have taken over smaller establishments which could not afford to make the changes required to maintain their licences. Older facilities may have inherent structural barriers to quality of life, such as narrow hallways and public ward accommodation. While the ideal is to have small, barrier-free facilities with a truly home-like design and location, the cost of replacing

larger facilities is prohibitive. The challenge is to assure reasonable quality of life regardless of the size and design of the existing structures.

4.4.4 Education and public awareness

Long-standing attitudes are hard to change. Negative images of institutional warehouses and of aging generally have made long-term care unattractive to professionals and the public alike. Education of all staff, administrators and management boards is vital to changing the attitudes that underlie the philosophy and operation of long-term care facilities.

Government can exercise considerable influence through standards governing institutional care and by promoting the education of professionals in long-term care and supporting the ongoing training of staff. Education grants to post-secondary educational establishments and to long-term care facilities are some means that have been undertaken. Admittedly, more is needed, especially in the face of institutional budget restrictions and resulting staff shortages.

4.4.5 Commercialization of long-term care

Criticisms of institutional long-term care tend to be directed to for-profit facilities. There have been reports that these facilities deny admission to persons requiring heavy levels of care because their care is less profitable, that they have poorly-trained aides, that they provide minimal staff training and that they generally sacrifice the quality of care in the name of profits.[5] Government prefers to provide incentives to the private sector to improve the quality of long-term care because these facilities may comprise a large proportion of long-term care institutions and because cost constraints prevent government from assuming control of long-term care from the private sector. Furthermore, in many instances, there is little convincing evidence that the quality of care is inferior in for-profit facilities in

comparison to non-profit institutions. As mentioned earlier, government aims to allow both business and the long-term care consumer to emerge as 'winners'.

CONCLUSION

All health care and social service sectors are feeling the pinch of financial constraints. More money will not be injected into the health care system. If the long-term care sector is to receive additional funds, these will be reallocated from other areas of health care, such as acute care hospitals. Whatever the funding level, the challenge is to distribute resources most effectively. Demands for higher and higher quality standards in long-term care at public expense may be difficult for governments to satisfy. Community groups and individuals may be increasingly called upon to do what government cannot.

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A CONVERGENCE OF PERSPECTIVES

by

Dorothy Pringle

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5. A CONVERGENCE OF PERSPECTIVES

Existing LTC [long-term care] institutions and some of the legislation which governs them are incompatible with the principles enshrined in the literature, the political speeches and the mission statements of the institutions themselves. Social intent is good but adaptation of professionals and institutions is slow to the point of being a barrier to progress. Never have such a large group of users been so in need of advocates.

So conclude Sutherland and Fulton[1] in their discussion of long-term care in Canada. One may reach a similar conclusion after reading each of the perspectives presented in this report. One in turn becomes aware of:

- the ability of many residents and families to articulate clearly what they require from long-term care facilities and their sense of frustration when legitimate needs are not met;

- the recognition by staff and administrators of what constitutes high quality long-term care and the feelings of conflicting pressures and of lack of resources; and

- the awareness of government officials of the difficulties in the long-term care sector and the attempt to satisfy consumers and providers, in the context of structures inherited from the past, evolving conceptions of health and well-being and financial constraints of health and social budgets.

Is it possible to reconcile all perspectives to reach solutions that meet the needs of the consumers in long-term care, allow service-providers to offer humane and individualized care and channel public resources equitably and cost-effectively? Let us briefly examine solutions that have been proposed.

5.1 Redirection to Community-based Long-term Care

Many provinces have announced plans for long-term care reform which will enhance home support and thus delay or prevent institutionalization. This shift in the focus of long-term care services will be combined with improved co-ordination between community and institutional care and with the provision of placement services to determine the type of care required by an individual. The redirection of long-term care holds much promise both for reducing the rate of institutionalization and for improving the quality of life of frail seniors and their caregivers at home. The success of this redirection will be dependent on the availability of services, particularly for caregivers to share the load of care of the frail and cognitively-impaired family members.

5.2 Organization and Funding of Institutional Long-term Care

Home support services have had the effect of minimizing the rate of admissions to institutional care of seniors with lower nursing requirements. This has meant that new admissions are more often for persons requiring heavy care. Changes in the organization and funding of care have been proposed to take into account the shift towards heavier care; in Ontario, for example, funding will be based on the actual service needs of the residents in a facility rather than on a pre-determined classification of the levels of care the facility provides. Ideally, funding will be more flexible and could be increased as the care requirements of residents change. Moreover, actual service-based funding is intended to eliminate the disincentive for facilities to deny admission to heavy-care cases or to transfer residents requiring more care than they normally deliver. It may be expected that this new funding procedure in Ontario will improve access to care, reduce institutional cost-cutting and contribute to residential stability as a person's care needs change over time.

5.3 Standards of Institutional Care

As the authors of the preceding chapters have pointed out, standards of care are a contested issue for several reasons. Maintaining standards that include nursing and personal care and respect for residents' rights and freedoms may be difficult to achieve simultaneously. Government representatives, long-term care administrators, professional associations and long-term care staff will need to clarify and resolve areas where there may be competing expectations in the standards. For instance, how can the long-term care facility ensure safety and security while ensuring that residents have choices and can take risks?

Secondly, there may be inconsistencies in care among different facilities which may be in part attributed to a profit motive; government monitoring and enforcement have not been entirely effective. Because commercial long-term care is likely to stay in a market-based economy, the challenge is to encourage the private sector to see a greater advantage in high quality service that yields long-term gains than in cutting corners to maximize immediate profitability. Again, the Ontario reform in long-term care should orient facilities in this direction by not permitting surpluses on funds allocated to nursing care, personal care and programs.

5.4 Blurring the Barriers between Institutional and Community-based Long-term Care

A cage is a cage, even if it is gilded. Too often, one has the impression that the long-term care facility is a world unto itself, cut off from the real world where people live and love. There are viable alternatives to the separation of the institution from the community; these include:

- improving regional distribution of long-term care facilities to allow residents to remain close to their home community;

- making supportive housing options more available; examples are independent apartments with on-site services, group homes and multi-level service communities where residents can move from fully-independent to assisted living units according to their needs;

- having institutions reorient their priorities and values so the emphasis is on creating a home for residents, with a focus on comfort, privacy and choice rather than on only meeting care standards;

- developing community services within the institution, such as day centres, meals-on-wheels and wheels-to-meals, respite care, convalescent and short-term stay beds; opening the institution to the community might serve to make facilities more vigilant about standards of care because they would be more visible to the community.

5.5 Professional Education and In-service Training

As long-term care facilities become increasingly devoted to the care of seniors with heavy-care needs, in particular for those with a significant degree of cognitive impairment, it will be essential to ensure that all staff possess a high level of gerontological knowledge and skills. Long-term care facilities themselves need to recruit (and adequately compensate) qualified personnel and further, to be open to the positive changes that these employees can bring about in the operation of the institution. In all provinces the role of the non-professional worker in the delivery of care and in the enhancement of the quality of life needs to be studied. Universities, colleges and professional associations need to assume an active role in developing educational opportunities in long-term care and in promoting attitudes favourable to this challenging field.

A promising development is that of the teaching nursing home, affiliated with a university, which allows for the education of health and social service professionals, for program innovation and research. By serving as a natural laboratory in long-term care, the teaching nursing home can become the 'gold standard' in institutional long-term care and the catalyst for positive change in other facilities.

CONCLUSION

Institutional long-term care has evolved considerably from its beginnings as the last refuge for the hopeless and the helpless. Increased public and professional awareness of the potential and the problems of long-term care and heightened government responsiveness can serve to bring it closer to the care we would want for ourselves. The critical issue is making long-term care client-centred rather than institution-centred. Canada prides itself on a high standard of living; this should extend to persons residing in long-term care facilities.

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Aging is everybody's business
Le vieillissement nous concerne tous

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Conseil consultatif national sur le troisième âge